NCI Family/Guardian Survey Regional Center Outcomes

Kern Regional Center Report

Fiscal Year 2016-17
Table of Contents

Quality Assessment Project and National Core Indicators™ ................................................................. 1

What is NCI? .................................................................................................................................................. 1

What is the NCI Family/Guardian Survey? ................................................................................................. 1

How were people selected to participate? ................................................................................................... 3

Data Analysis ................................................................................................................................................ 4

Weighting ..................................................................................................................................................... 4

Limitations of Data ....................................................................................................................................... 4

What is Contained in This Report? ............................................................................................................. 5

Demographics of the Family Member ......................................................................................................... 6

  GRAPH 1. FAMILY MEMBER’S RESIDENCE ......................................................................................... 7
  GRAPH 2. FAMILY MEMBER’S RESIDENCE (CONTINUED) ................................................................. 7
  GRAPH 3. FAMILY MEMBER’S RESIDENTIAL DESIGNATION (URBAN/SUBURBAN OR RURAL) ..... 7
  GRAPH 4. FAMILY MEMBER’S AGE .................................................................................................... 7
  GRAPH 5. FAMILY MEMBER’S GENDER ............................................................................................... 8
  GRAPH 6. FAMILY MEMBER’S DISABILITIES (CA QUALIFYING CONDITIONS) .............................. 8
  GRAPH 7. FAMILY MEMBER’S TYPES OF DISABILITIES (CONTINUED) ........................................ 8
  GRAPH 8. FAMILY MEMBER’S TYPES OF DISABILITIES (CONTINUED) ........................................ 8
  GRAPH 9. FAMILY MEMBER’S HEALTH CONDITIONS .................................................................. 9
  GRAPH 10. FAMILY MEMBER’S HEALTH CONDITIONS (CONTINUED) ...................................... 9
  GRAPH 11. FAMILY MEMBER’S RACE AND ETHNICITY ................................................................. 9
  GRAPH 12. FAMILY MEMBER’S PREFERRED MEANS OF COMMUNICATION .............................. 9
  GRAPH 13. FAMILY MEMBER’S PREFERRED LANGUAGE ................................................................. 10
  GRAPH 14. FAMILY MEMBER’S PREFERRED LANGUAGE (CONTINUED) .................................... 10
  GRAPH 15. FAMILY MEMBER’S PREFERRED LANGUAGE (CONTINUED) .................................... 10
  GRAPH 16. FAMILY MEMBER HAS LEGAL COURT APPOINTED GUARDIAN OR CONSERVATOR .. 10
  GRAPH 17. GUARDIAN OR CONSERVATOR RELATIONSHIP TO FAMILY MEMBER .................... 11
GRAPH 18. FAMILY MEMBER'S HIGHEST LEVEL OF EDUCATION
GRAPH 19. FAMILY MEMBER'S TYPICAL DAY ACTIVITIES: PAID INDIVIDUAL JOB IN THE COMMUNITY
GRAPH 20. FAMILY MEMBER'S TYPICAL DAY ACTIVITIES: PAID SMALL GROUP JOB IN A COMMUNITY-BASED SETTING
GRAPH 21. FAMILY MEMBER'S TYPICAL DAY ACTIVITY: UNPAID ACTIVITY IN A COMMUNITY-BASED SETTING
GRAPH 22. FAMILY MEMBER'S TYPICAL DAY ACTIVITIES: PAID ACTIVITY IN A FACILITY-BASED SETTING
GRAPH 23. FAMILY MEMBER'S TYPICAL DAY ACTIVITIES: UNPAID ACTIVITY IN A FACILITY-BASED SETTING
GRAPH 24. FAMILY MEMBER'S TYPICAL DAY ACTIVITIES: SCHOOL
GRAPH 25. FAMILY MEMBER'S TYPICAL DAY ACTIVITIES: STAYS AT HOME
GRAPH 26. FAMILY MEMBER'S SUPPORT NEEDS FOR SELF-INJURIOUS, DISRUPTIVE, AND/OR DESTRUCTIVE BEHAVIORS
GRAPH 27. FAMILY MEMBER'S LEVEL OF HELP NEEDED WITH PERSONAL CARE ACTIVITIES (FOR EXAMPLE, BATHING, DRESSING, EATING)
GRAPH 28. FAMILY MEMBER'S NEED FOR HELP WITH OTHER DAILY ACTIVITIES (FOR EXAMPLE, SCHEDULING, MANAGING MONEY, OR SHOPPING)

Demographics of Respondent
GRAPH 29. RESPONDENT'S AGE
GRAPH 30. RESPONDENT'S HEALTH
GRAPH 31. RESPONDENT'S RELATIONSHIP TO FAMILY MEMBER
GRAPH 32. RESPONDENT'S FREQUENCY OF VISITS WITH FAMILY MEMBER
GRAPH 33. RESPONDENT'S HIGHEST LEVEL OF EDUCATION
GRAPH 34. TOTAL TAXABLE HOUSEHOLD INCOME OF WAGE EARNERS IN THE PAST YEAR
GRAPH 35. APPROXIMATELY HOW MUCH OUT-OF-POCKET (UNREIMBURSED) MONEY DID YOU SPEND LAST YEAR ON YOUR FAMILY MEMBER'S MEDICAL SERVICES, EQUIPMENT, SUPPLIES, THERAPIES, AND OTHER SERVICES?
GRAPH 36. WHICH SERVICES OR THERAPIES DO YOU PAY FOR OUT-OF-POCKET (UNREIMBURSED)?
GRAPH 37. WHICH SERVICES OR THERAPIES DO YOU PAY FOR OUT-OF-POCKET (CONTINUED)?

Services and Supports Received
GRAPH 38. SERVICES AND SUPPORTS RECEIVED FROM THE REGIONAL CENTER
GRAPH 39. ADDITIONAL SERVICES AND SUPPORTS RECEIVED

Information and Planning
GRAPH 40. DO YOU GET ENOUGH INFORMATION TO HELP YOU TAKE PART IN PLANNING SERVICES FOR YOUR FAMILY?
GRAPH 41. IS THE INFORMATION YOU GET ABOUT SERVICES AND SUPPORTS EASY TO UNDERSTAND?
GRAPH 42. DO STAFF OR THE RESIDENTIAL AGENCY KEEP YOU INFORMED ABOUT HOW YOUR FAMILY MEMBER IS DOING?
GRAPH 43. DOES THE CASE MANAGER/SERVICE COORDINATOR RESPECT YOUR FAMILY'S CHOICES AND OPINIONS?
GRAPH 44. DO YOU NEED HELP PLANNING FOR YOUR FAMILY MEMBER'S FUTURE WITH RESPECT TO ANY OF THE FOLLOWING?
Access and Delivery

Graph 45. Do you need help planning for your family member's future with respect to any of the following? (Continued) ................................................................. 22

Graph 46. In the past year, did your family member move out of the family home for the first time? .......................................................................................................................... 22

Graph 47. Does your family member have an Individual Program Plan (IPP)? ......................................................................................................................... 22

Graph 48. If your family member has an IPP, does the IPP include all the services and supports your family member needs? ........................................................................... 23

Graph 49. If your family member has an IPP, does your family member get all of the services listed in the IPP? .................................................................................... 23

Graph 50. If your family member has an IPP, did you or another family member (beside your family member with a disability) help make the IPP? .................................................. 23

Graph 51. If your family member has an IPP, did your family member help make the IPP? ................................................................................................................. 23

Graph 52. Did you discuss how to handle emergencies (such as a medical emergency or a natural disaster) at your family member's last IPP meeting? .......................................................... 24

Graph 53. If your family member transitioned out of school services during the past year, did he/she have a transition plan? ................................................................................... 24

Graph 54. Does your family member have enough supports (for example, support workers, community resources) to work or volunteer in the community? ................................................. 24

Graph 55. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or a natural disaster? ................................................................. 24

Graph 56. Are you or your family member able to contact his/her support workers when you want to? .................................................................................................................. 26

Graph 57. Are you or your family member able to contact your family member's case manager/service coordinator when you want to? ................................................................. 26

Graph 58. Do support workers come and leave when they are supposed to? ................................................................................................................................. 26

Graph 59. Do services and supports change when your family member's needs change? ................................................................................................................................. 26

Graph 60. Do support workers speak to you in a way that you understand? ................................................................................................................................. 27

Graph 61. Are services delivered in a way that is respectful of your family's culture? ................................................................................................................................. 27

Graph 62. If your family member does not communicate verbally (for example, uses gestures or sign language), are there support workers who can communicate with him/her? ................................................................................................................................. 27

Graph 63. Do support workers have the right information and skills to meet your family's needs? ................................................................................................................................. 27

Graph 64. Does your family member have access to the special equipment or accommodations that s/he needs (for example, wheelchair, ramp, communication board)? ................................................................................................................................. 28

Graph 65. Can your family member see health professionals when needed (for example, doctor, dentist, psychologist)? ................................................................................................................................. 28

Graph 66. Does your family member's primary care doctor understand his/her needs related to his/her disability? ................................................................................................................................. 28

Graph 67. Do you have access to dental services for your family member? ................................................................................................................................. 28

Graph 68. Does your family member's dentist understand his/her needs related to his/her disability? ................................................................................................................................. 29

Graph 69. If your family member takes medications, do you know what they're for? ................................................................................................................................. 29

Graph 70. If your family member takes medications, do you, your family member or someone else in your family know what is needed to safely take the medications (when it should be taken, how much to take, potential side effects)? ................................................................................................................................. 29

Graph 71. If your family member uses mental health services, does the mental health professional (for example, psychologist, psychiatrist, counselor) understand your family member's needs related to his/her disability? ................................................................................................................................. 29
Choice, Decision Making and Control

GRAPH 72. DOES YOUR FAMILY GET THE SUPPORT NEEDED? .......................................................... 30

GRAPH 73. DOES THE AGENCY PROVIDING RESIDENTIAL SUPPORTS TO YOUR FAMILY MEMBER INVOLVE HIM/HER IN IMPORTANT DECISIONS? .......................... 31
GRAPH 74. CAN YOUR FAMILY CHOOSE OR CHANGE THE AGENCY THAT PROVIDES YOUR FAMILY MEMBER’S SERVICES? ................................................................. 31
GRAPH 75. CAN YOUR FAMILY CHOOSE OR CHANGE YOUR FAMILY MEMBER’S SUPPORT WORKERS? .............................................................. 31
GRAPH 76. DOES YOUR FAMILY DIRECTLY MANAGE SUPPORT WORKERS (FOR EXAMPLE, HIRING AND DECIDING SCHEDULE)? ......................................................... 32
GRAPH 77. DO SERVICE PROVIDERS FOR YOUR FAMILY MEMBER WORK TOGETHER TO PROVIDE SUPPORT? ............................................................ 32
GRAPH 78. DID YOU, YOUR FAMILY MEMBER, OR SOMEONE ELSE IN YOUR FAMILY CHOOSE YOUR FAMILY MEMBER’S CASE MANAGER/SERVICE COORDINATOR? ....... 33

Involvement in the Community

GRAPH 79. DOES YOUR FAMILY MEMBER TAKE PART IN ACTIVITIES IN THE COMMUNITY (FOR EXAMPLE, GOING OUT TO A RESTAURANT, MOVIE, OR SPORTING EVENT)?.... 34
GRAPH 80. FOR YOUR FAMILY MEMBER, WHAT ARE THE OBSTACLES OR BARRIERS TO PARTICIPATION IN ACTIVITIES IN THE COMMUNITY? ................................. 34
GRAPH 81. DOES YOUR FAMILY MEMBER HAVE FRIENDS OTHER THAN PAID SUPPORT WORKERS OR FAMILY? ...................................................... 35
GRAPH 82. IN YOUR COMMUNITY, ARE THERE RESOURCES THAT YOUR FAMILY CAN USE THAT ARE NOT PROVIDED BY THE REGIONAL CENTER? ........................... 35
GRAPH 83. DOES YOUR FAMILY TAKE PART IN ANY FAMILY-TO-FAMILY NETWORKS IN YOUR COMMUNITY? ............................................................ 36

Satisfaction

GRAPH 84. OVERALL, ARE YOU SATISFIED WITH THE SERVICES AND SUPPORTS YOUR FAMILY MEMBER CURRENTLY RECEIVES? ......................................................... 37
GRAPH 85. DO YOU KNOW THE PROCESS FOR FILING A COMPLAINT OR GRIEVANCE ABOUT PROVIDER AGENCIES OR STAFF? ................................................... 37
GRAPH 86. IF A COMPLAINT OR GRIEVANCE RELATED TO YOUR FAMILY MEMBER WAS FILED OR RESOLVED IN THE PAST YEAR, ARE YOU SATISFIED WITH THE WAY IT WAS HANDLED AND RESOLVED? ...................................................... 37
GRAPH 87. DO YOU KNOW HOW TO REPORT ABUSE OR NEGLECT RELATED TO YOUR FAMILY MEMBER? .............................................................. 38
GRAPH 88. WITHIN THE PAST YEAR, WAS A REPORT OF ABUSE OR NEGLECT FILED ON BEHALF OF YOUR FAMILY MEMBER? ...................................................... 38
GRAPH 89. DO YOU FEEL THAT SERVICES AND SUPPORTS HAVE MADE A POSITIVE DIFFERENCE IN THE LIFE OF YOUR FAMILY MEMBER? ........................................... 38
GRAPH 90. HAVE THE SERVICES OR SUPPORTS THAT YOUR FAMILY MEMBER RECEIVED DURING THE PAST YEAR BEEN REDUCED, SUSPENDED, OR TERMINATED? .......... 39
GRAPH 91. IF SERVICES OR SUPPORTS RECEIVED BY THE FAMILY MEMBER WERE REDUCED, SUSPENDED OR TERMINATED DURING THE PAST YEAR, DID THE REDUCTION, SUSPENSION, OR TERMINATION OF THESE SERVICES OR SUPPORTS AFFECT YOUR FAMILY OR YOUR FAMILY MEMBER NEGATIVELY? .................................................. 39
GRAPH 92. HAVE THE SERVICES OR SUPPORTS THAT YOUR FAMILY MEMBER RECEIVED BEEN INCREASED IN THE PAST YEAR? .......................................................... 40
GRAPH 93. ARE SERVICES AND SUPPORTS HELPING YOUR FAMILY MEMBER TO LIVE A GOOD LIFE? .............................................................. 40

CA Specific Questions: Cultural Competency

GRAPH 94. DID YOU GET A COPY OF YOUR IPP IN YOUR PREFERRED LANGUAGE? .......................................................... 41
GRAPH 95. ARE THERE SUPPORT WORKERS AVAILABLE WHO CAN SPEAK TO YOU IN YOUR PREFERRED LANGUAGE? .......................................................... 41
GRAPH 96. HAS YOUR FAMILY MEMBER MOVED FROM A DEVELOPMENTAL CENTER (DC) TO THE COMMUNITY IN THE PAST FIVE YEARS? ........................................... 41
GRAPH 97. ARE THERE SUPPORT WORKERS AVAILABLE WHO CAN SPEAK TO YOUR FAMILY MEMBER IN YOUR PREFERRED LANGUAGE? ................................. 42
GRAPH 98. WAS YOUR FAMILY MEMBER AVAILABLE TO CHOOSE ANOTHER PERSON TO HELP THEM WITH DAILY ACTIVITIES (EXAMPLES: GETTING DRESSED, WASHING OR CLEANING)? ................. 42
GRAPH 99. WAS YOUR FAMILY MEMBER ABLE TO CHOOSE ANOTHER PERSON TO HELP THEM WITH DAILY ACTIVITIES (EXAMPLES: GETTING DRESSED, WASHING OR CLEANING)? .......................... 42

National Core Indicators™

Regional Center Results: FY16/17

Family/Guardian Survey Regional Center Results: FY16/17 | v
GRAPH 97. HOW LONG HAS YOUR FAMILY MEMBER LIVED IN THE COMMUNITY?

GRAPH 98. HOW DO YOU LIKE YOUR FAMILY MEMBER'S NEW HOME?

GRAPH 99. ARE THE SERVICES THAT WERE DECIDED UPON IN THE INDIVIDUAL DEVELOPMENT TEAM (IDT) MEETING (COMMUNITY TRANSITION PLANNING MEETING) BEING DELIVERED TO YOUR FAMILY MEMBER IN THE COMMUNITY?
Quality Assessment Project and National Core Indicators™

This report contains regional center level results from California’s statewide National Core Indicators Family/Guardian Survey data collection from fiscal year 2016-17 (FY 16/17) in accordance with Welfare and Institutions Code (WIC), Section 4571. WIC, Section 4571 directs the Department of Developmental Services (DDS) to collect accurate, reliable, and valid consumer and family satisfaction measures as well as individual outcome data. In California, data from this project will be used to review and benchmark statewide and regional center developmental disability service system performance. This report shows Family/Guardian Survey findings from Kern Regional Center compared to the California statewide and NCI averages. Regional centers can use this report to help guide strategic planning and monitor systemic changes.

What is NCI?

The National Core Indicators (NCI) program is a voluntary effort by state developmental disability agencies to measure and track their performance using a standardized set of consumer and family/guardian surveys with nationally validated measures. The effort is coordinated by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI).

NCI has developed more than 100 standard performance measures (or ‘indicators’) that states use to assess the outcomes of services for individuals and families, including outcomes in the areas of employment, rights, service planning, community inclusion, choice, health, and safety. In 2016-17 a total of 46 states, the District of Columbia and 22 sub-state entities participated in NCI.

What is the NCI Family/Guardian Survey?

The NCI Family/Guardian Survey is used to gather data on family outcomes. It is mailed to families and guardians who have an adult family member who does not live in the family home and receives at least one service other than case management from the state

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1 Refer to the California Family/Guardian Survey Report FY 16/17 for information about Quality Assessment Project implementation, NCI and California’s statewide results.
developmental disabilities agency. The survey collects demographic information on both the individual receiving services and the person who fills out the survey (the ‘respondent’) as well as information on services and supports received. The survey is continually refined and tested to ensure it is valid and reliable.

In 2016-17, a total of 9,194 Family/Guardian Surveys were completed across 12 states. The survey contained six groupings of questions (“sub-domains”) that probe specific areas of quality service provision: information and planning, access and delivery of services, choice and control, community connections, satisfaction, and outcomes (see Table A1). Respondents also had the option of writing open-ended comments concerning their family's participation in the service system.

Table A1. NCI Family Survey – sub-domains and concern statements

<table>
<thead>
<tr>
<th>Sub-Domain</th>
<th>Concern</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information and Planning</td>
<td>Families/family members with disabilities have the information and support necessary to plan for their services and supports.</td>
</tr>
<tr>
<td>Access &amp; Support Delivery</td>
<td>Families/family members with disabilities get the services and supports they need.</td>
</tr>
<tr>
<td>Choice, Decision Making &amp; Control</td>
<td>Families/family members with disabilities determine the services and supports they receive and the individuals or agencies who provide them.</td>
</tr>
<tr>
<td>Involvement in the Community</td>
<td>Family members with disabilities use integrated community services and participate in everyday community activities.</td>
</tr>
<tr>
<td>Satisfaction</td>
<td>Families/family members with disabilities receive adequate and satisfactory supports.</td>
</tr>
<tr>
<td>Outcomes</td>
<td>Individual and family supports make a positive difference in the lives of families.</td>
</tr>
</tbody>
</table>

2 States that conducted the Family/Guardian Survey in 2016-17 were: AZ, CA, FL, GA, KY, LA, MD, NC, NJ, PA, SD and VA.
How were people selected to participate?

In California, all eligible families were mailed a survey for the Family/Guardian Survey FY16/17. The State Council on Developmental Disabilities (SCDD) mailed out the paper survey to 19,799 eligible families. A total of 4,062 usable surveys across the 21 regional centers were returned.

All participating states were asked to administer the survey to a random sample of at least 1,000 families, all of whom have an adult family member with an intellectual or developmental disability who lives somewhere other than the family home and receives at least one direct service or support other than service coordination.

Beginning in 2016-17, states had a choice of mailing paper surveys to families selected in their sample, sending a URL link for families to complete surveys online (referred to as “direct entry”), or both. In previous years, states only had the option to mail paper surveys. A total of five states (not including California) had at least a portion of surveys completed via direct entry mode.³

All states mailed out a paper survey to families selected in their sample. A sample size of 1,000 was recommended with the expectation of a 40% return rate or greater (yielding 400 or more usable responses per state). However, most states decided to sample more than 1,000 families, expecting a lower response rate than 40%. A final sample size of 400 would guarantee a +/- 5% margin of error and a 95% confidence level when interpreting the results. Both the confidence level and margin of error used are widely accepted standards for reviewing results, regardless of population size. States with fewer than 1,000 potential respondent families were instructed to send surveys to all eligible families. With response rates lower than expected, we included in our national reports those states that submitted fewer than 400 surveys up to a margin of error of no greater than +/- 7%.

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³ States that used the direct entry or mail and direct entry options were: KY, LA, NC, NJ, and SD. For more information on response rates and mode, please see the Methodology section within the national edition of the 2016-17 Family/Guardian Survey Report.
Data Analysis

Surveys received from the state were considered valid, based on the following two criteria:

1. The respondent indicated the individual with an intellectual or developmental disability receiving services lived somewhere other than the family home.
2. At least a portion of survey questions were answered aside from demographic information.

Questions left blank or marked ‘not applicable’ are not included in analysis. For most questions, ‘don’t know’ responses were excluded from analysis. Two questions in the Satisfaction section combine ‘no’ and ‘don’t know’ responses, those questions are asterisked. Data are not shown for items if the regional center had fewer than 20 respondents.

Weighting

In previous years, the NCI average was calculated as the simple arithmetic mean of all state means (an approach known as “average of averages”). This year, the approach has been enhanced to take into account the relative numbers of people receiving services through participating states’ systems. Beginning this year, the NCI averages contained in this report are “weighted” means. Applying statistical weights allows a state that provides services to a larger number of people (but is represented in the data by a sample of the same size as other states) to have a higher influence on the overall NCI average—that is, the state’s contribution to the NCI average is proportional to its service population. The weights used in calculations for this report were developed using each participating state’s number of survey respondents and its total survey-eligible population.

Please note: the California Averages included in this report are unweighted averages across the state.

Limitations of Data

The NCI Family/Guardian Survey is a tool for assessing system-wide performance. It is not intended to be used to monitor individuals or providers. The NCI Average should not be interpreted as defining or providing a benchmark for “acceptable” levels of performance or
satisfaction. Instead, it describes average levels of performance or satisfaction across the State and regional center; it is up to public managers, policy-makers, and other stakeholders to use the data to determine programmatic and policy-related priorities.

**What is Contained in This Report?**

This report illustrates 2016-17 NCI Family/Guardian Survey demographic and outcome results from Kern Regional Center compared to the CA statewide average and the weighted NCI average.

The number of responses per each question by regional center, state, and across NCI states are included in each chart. All results are shown in chart form. In charts, “N” refers to the total number of respondents. All state and national data results for this survey can be found online at: http://www.dds.ca.gov/QA/.
Demographics of the Family Member

This section provides demographic profiles of the family member about whom the survey was completed.
**Note, abbreviated residential categories are as follows: Institutional Care Facility (ICF); Community Care Facility (CCF); own home or apartment ILS/SLS. CCF corresponds to NCI group home settings.**

**Note, abbreviated residential categories are as follows: Family Home Agency (FHA); Skilled Nursing Facility (SNF). FHA corresponds to NCI foster care or host home category. SNF corresponds to NCI nursing homes category.**
GRAPH 5.

Family Member's Gender

Male
- KRC (N = 158)
- CA Average (N = 4018)
- NCI Average (N = 9067)

Female
- 57%
- 60%
- 59%
- 43%
- 41%
- 41%

GRAPH 6. * ±

Family Member’s Disabilities (CA Qualifying Conditions)

- Intellectual Disability
  - KRC
  - CA Average
  - NCI Average
  - 63%
  - 68%
  - 74%

- Autism Spectrum Disorder
  - KRC
  - CA Average
  - NCI Average
  - 30%
  - 28%
  - 25%

- Cerebral Palsy
  - KRC
  - CA Average
  - NCI Average
  - 15%
  - 17%
  - 17%

- Epilepsy
  - KRC
  - CA Average
  - NCI Average
  - 26%
  - 26%
  - 28%

GRAPH 7. *

Family Member’s Disabilities

- Mental Illness or Psychiatric Disorder
  - KRC
  - CA Average
  - NCI Average
  - 27%
  - 28%
  - 33%

- Limited or No Vision
  - KRC
  - CA Average
  - NCI Average
  - 8%
  - 8%
  - 9%

- Severe or Profound Hearing Loss
  - KRC
  - CA Average
  - NCI Average
  - 4%
  - 5%
  - 7%

- Brain Injury
  - KRC
  - CA Average
  - NCI Average
  - 9%
  - 11%
  - 11%

GRAPH 8. *

Family Member’s Disabilities

- Chemical Dependency
  - KRC
  - CA Average
  - NCI Average
  - 1%
  - 1%
  - 1%

- Down Syndrome
  - KRC
  - CA Average
  - NCI Average
  - 1%
  - 1%
  - 1%

- Prader-Willi Syndrome
  - KRC
  - CA Average
  - NCI Average
  - 1%
  - 1%
  - 1%

- Fetal Alcohol Spectrum Disorder
  - KRC
  - CA Average
  - NCI Average
  - 1%
  - 1%
  - 1%

- Other
  - KRC
  - CA Average
  - NCI Average
  - 1%
  - 1%
  - 1%

* Categories are not mutually exclusive, therefore N is not shown.
± Epilepsy corresponds to NCI category ‘seizure disorder/neurological condition’.
**GRAPH 9.**

Family Member’s Health Conditions

<table>
<thead>
<tr>
<th>Condition</th>
<th>KRC</th>
<th>CA Average</th>
<th>NCI Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiovascular Disease</td>
<td>11%</td>
<td>7%</td>
<td>9%</td>
</tr>
<tr>
<td>Diabetes</td>
<td>24%</td>
<td>17%</td>
<td>19%</td>
</tr>
<tr>
<td>Cancer</td>
<td>9%</td>
<td>5%</td>
<td>5%</td>
</tr>
<tr>
<td>High Blood Pressure</td>
<td>34%</td>
<td>28%</td>
<td>30%</td>
</tr>
<tr>
<td>High Cholesterol</td>
<td>29%</td>
<td>21%</td>
<td>31%</td>
</tr>
</tbody>
</table>

**GRAPH 10.**

Family Member’s Health Conditions

<table>
<thead>
<tr>
<th>Condition</th>
<th>KRC</th>
<th>CA Average</th>
<th>NCI Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dysphagia</td>
<td>8%</td>
<td>9%</td>
<td>12%</td>
</tr>
<tr>
<td>Pressure Ulcers</td>
<td>0%</td>
<td>2%</td>
<td>2%</td>
</tr>
<tr>
<td>Alzheimer’s Disease or Other Dementia</td>
<td>3%</td>
<td>3%</td>
<td>3%</td>
</tr>
<tr>
<td>Oral Health or Dental Problems</td>
<td>8%</td>
<td>18%</td>
<td>18%</td>
</tr>
<tr>
<td>Sleep Apnea</td>
<td>9%</td>
<td>13%</td>
<td>13%</td>
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<tr>
<td>Other</td>
<td>32%</td>
<td>33%</td>
<td>38%</td>
</tr>
</tbody>
</table>

**GRAPH 11.**

Family Member’s Race And Ethnicity

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>KRC</th>
<th>CA Average</th>
<th>NCI Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>American Indian or Alaska</td>
<td>4%</td>
<td>2%</td>
<td>2%</td>
</tr>
<tr>
<td>Asian</td>
<td>7%</td>
<td>8%</td>
<td>8%</td>
</tr>
<tr>
<td>Black or African-American</td>
<td>4%</td>
<td>6%</td>
<td>10%</td>
</tr>
<tr>
<td>Hawaiian or Pacific Islander</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>White</td>
<td>21%</td>
<td>21%</td>
<td>76%</td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>17%</td>
<td>14%</td>
<td>7%</td>
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<tr>
<td>Other</td>
<td>3%</td>
<td>2%</td>
<td>2%</td>
</tr>
</tbody>
</table>

**GRAPH 12.**

Family Member’s Preferred Means Of Communication

<table>
<thead>
<tr>
<th>Communication Method</th>
<th>KRC</th>
<th>CA Average</th>
<th>NCI Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spoken</td>
<td>77%</td>
<td>78%</td>
<td>74%</td>
</tr>
<tr>
<td>Gestures or Body Language</td>
<td>15%</td>
<td>15%</td>
<td>19%</td>
</tr>
<tr>
<td>Sign Language or Finger Spelling</td>
<td>3%</td>
<td>2%</td>
<td>2%</td>
</tr>
<tr>
<td>Communication Aid or Device</td>
<td>1%</td>
<td>1%</td>
<td>1%</td>
</tr>
<tr>
<td>Other</td>
<td>4%</td>
<td>4%</td>
<td>4%</td>
</tr>
</tbody>
</table>

* Categories are not mutually exclusive, therefore N is not shown.
± NCI race and ethnicity categories are based on the Census model; CA records Hispanic/Latino as a race group.
California-specific question

Full guardianship is not applicable in California.
"Paid individual job in the community" is defined as: a person working at an individual job in a local business alongside peers who do not have disabilities. Job is part of the typical labor market (e.g., competitive employment).

"Paid small group job in a community-based setting" is defined as: an activity is done in an integrated setting, as part of a group of not more than 8 people with disabilities (e.g., enclave, work crew).
"Unpaid Activity in a Community-based Setting" may include: volunteering, skills training, and staff-supported community connections.

"Paid activity in a facility-based setting" may include activities in a workshop, activity center, or business that primarily hires people with disabilities.

"Unpaid activity in a facility-based setting" may include day habilitation, senior programs or drop-in centers.
Demographics of Respondent

This section provides demographic information about the respondent.
GRAPH 33.

Respondent's Highest Level Of Education

GRAPH 34.

Total Taxable Household Income Of Wage Earners In The Past Year

GRAPH 35. ∞

Out-Of-Pocket Expenses For Family Member’s Care In The Past Year

GRAPH 36. ∞ *

Services And Supports Paid For Out-Of-Pocket

∞ California-specific question

*Categories are not mutually exclusive
GRAPH 37. ∞ *

Services And Supports Paid For Out-Of-Pocket

- Afterschool Care: 0% (KRC), 0% (CA Average)
- Educational Expenses: 6% (KRC), 4% (CA Average)
- Medical and/or dental expenses: 52% (KRC)
- Parent Training: 0% (KRC), 1% (CA Average)
- Transportation Support: 28% (KRC), 32% (CA Average)
- Other: 28% (KRC), 33% (CA Average)

∞ California-specific question
*Categories are not mutually exclusive
Services and Supports Received

*This section provides information about the services and supports received.*
GRAPH 38. **

*Categories are not mutually exclusive, therefore N is not shown

**Note, NCI average refers to DD agency support
Information and Planning

*FAMILIES AND FAMILY MEMBERS WITH DISABILITIES HAVE THE INFORMATION AND SUPPORT NECESSARY TO PLAN FOR THEIR SERVICES AND SUPPORTS.*
GRAPH 44.*

Respondent Needs Help Planning For Family Member’s Future Needs

- Employment
  - KRC (N = 76)
  - CA Average (N = 2006)
  - NCI Average (N = 4306)
- Financial
  - KRC (N = 76)
  - CA Average (N = 2006)
  - NCI Average (N = 4306)
- Housing
  - KRC (N = 76)
  - CA Average (N = 2006)
  - NCI Average (N = 4306)
- Legal
  - KRC (N = 76)
  - CA Average (N = 2006)
  - NCI Average (N = 4306)

GRAPH 45.*

Respondent Needs Help Planning For Family Member’s Future Needs

- Medical
  - KRC (N = 76)
  - CA Average (N = 2006)
  - NCI Average (N = 4306)
- Social or Relationships
  - KRC (N = 76)
  - CA Average (N = 2006)
  - NCI Average (N = 4306)
- Transition from School
  - KRC (N = 76)
  - CA Average (N = 2006)
  - NCI Average (N = 4306)
- Recreation or Having Fun
  - KRC (N = 76)
  - CA Average (N = 2006)
  - NCI Average (N = 4306)
- Other
  - KRC (N = 76)
  - CA Average (N = 2006)
  - NCI Average (N = 4306)

GRAPH 46.

In Past Year, Family Member Moved Out Of Family Home For First Time

- Yes
  - KRC (N = 148)
  - CA Average (N = 3820)
  - NCI Average (N = 8699)
- No
  - KRC (N = 148)
  - CA Average (N = 3820)
  - NCI Average (N = 8699)

GRAPH 47.

Family Member Has An IPP

- Yes
  - KRC (N = 108)
  - CA Average (N = 3057)
  - NCI Average (N = 7111)
- No
  - KRC (N = 108)
  - CA Average (N = 3057)
  - NCI Average (N = 7111)

*Categories are not mutually exclusive
Access and Delivery

*Families and family members with disabilities get the services and supports they need.*
Graph 72.

* Categories are not mutually exclusive, therefore N is not shown.
Choice, Decision Making and Control

FAMILIES AND FAMILY MEMBERS WITH DISABILITIES DETERMINE THE SERVICES AND SUPPORTS THEY RECEIVE AND THE INDIVIDUALS OR AGENCIES WHO PROVIDE THEM.
GRAPH 77.

Family Member’s Service Providers Work Together To Provide Supports

- Yes: 90% KRC (N = 77), 92% CA Average (N = 2337), 94% NCI Average (N = 5750)
- No: 10% KRC (N = 77), 8% CA Average (N = 2337), 6% NCI Average (N = 5750)

GRAPH 78.

Respondent, Family Member With A Disability Or Another Family Member Chose Or Can Change Case Manager/Service Coordinator

- Chose Case Manager/Service Coordinator: 9% KRC (N = 115), 8% CA Average (N = 2858), 19% NCI Average (N = 6814)
- Did Not Choose Case Manager/Service Coordinator but Can Change If Wanted: 55% KRC (N = 115), 63% CA Average (N = 2858), 52% NCI Average (N = 6814)
- Did Not Choose Case Manager/Service Coordinator and Cannot Change If Wanted: 37% KRC (N = 115), 29% CA Average (N = 2858), 29% NCI Average (N = 6814)
Involvement in the Community

*Family members with disabilities use integrated community services and participate in everyday community activities.*
GRAPH 79. 

**Family Member Takes Part In Community Activities**

- Yes: KRC (N = 132), CA Average (N = 3555), NCI Average (N = 8260)
  - KRC: 87%
  - CA Average: 88%
  - NCI Average: 91%
- No: 13% (KRC), 12% (CA Average), 9% (NCI Average)

GRAPH 80. *

**Obstacles Or Barriers To Family Member's Participation In Community Activities**

- Lack of Transport: KRC 65%, CA Average 67%, NCI Average 76%
- Cost: KRC 59%, CA Average 64%, NCI Average 70%
- Lack of Support Staff: KRC 76%, CA Average 72%, NCI Average 69%
- Stigma: KRC 86%, CA Average 85%, NCI Average 87%
- Other: KRC 63%, CA Average 60%, NCI Average 53%

GRAPH 81. 

**Family Member Has Friends Or Relationships With People Other Than Paid Support Workers Or Family**

- Yes: KRC (N = 124), CA Average (N = 3317), NCI Average (N = 7749)
  - KRC: 62%
  - CA Average: 65%
  - NCI Average: 67%
- No: 38% (KRC), 35% (CA Average), 33% (NCI Average)

GRAPH 82. **

**There Are Resources In The Community Family Can Use That Are Not Provided By The Regional Center**

- Yes: KRC (N = 93), CA Average (N = 2299), NCI Average (N = 5508)
  - KRC: 78%
  - CA Average: 78%
  - NCI Average: 78%
- No: 22% (KRC), 22% (CA Average), 22% (NCI Average)

---

*Categories are not mutually exclusive, therefore N is not shown.

** Note, NCI average refers to DD agency support
GRAPH 83.

Family Takes Part In Family-to-family Networks

- KRC (N = 111): 16% Yes, 18% No
- CA Average (N = 3105): 17% Yes, 18% No
- NCI Average (N = 6998): 84% Yes, 83% No, 82% No
Satisfaction

_FAMILIES AND FAMILY MEMBERS WITH DISABILITIES RECEIVE ADEQUATE AND SATISFACTORY SUPPORTS._
For this question, ‘No’ and Don’t Know’ responses were combined.
GRAPH 92. Services Or Supports Were Increased In The Past Year

<table>
<thead>
<tr>
<th></th>
<th>KRC (N = 94)</th>
<th>CA Average (N = 2566)</th>
<th>NCJ Average (N = 6179)</th>
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<tr>
<td>Yes</td>
<td>16%</td>
<td>16%</td>
<td>18%</td>
</tr>
<tr>
<td>No</td>
<td>84%</td>
<td>84%</td>
<td>82%</td>
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</table>

GRAPH 93. Services And Supports Help Family Member Live A Good Life

<table>
<thead>
<tr>
<th></th>
<th>KRC (N = 118)</th>
<th>CA Average (N = 3387)</th>
<th>NCJ Average (N = 7952)</th>
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</thead>
<tbody>
<tr>
<td>Yes</td>
<td>89%</td>
<td>93%</td>
<td>95%</td>
</tr>
<tr>
<td>No</td>
<td>11%</td>
<td>7%</td>
<td>5%</td>
</tr>
</tbody>
</table>
CA Specific Questions: Cultural Competency
GRAPH 98.

How Much Respondent Likes Family Member's New Home

- Extremely: KRC (N = 46) - 35%, CA Average (N = 1221) - 32%
- Very Much: KRC (N = 46) - 46%, CA Average (N = 1221) - 50%
- Somewhat: KRC (N = 46) - 17%, CA Average (N = 1221) - 15%
- Very Little: KRC (N = 46) - 0%, CA Average (N = 1221) - 2%
- Not at All: KRC (N = 46) - 2%, CA Average (N = 1221) - 2%

GRAPH 99.

There Are Services That Were Decided Upon In The IDT Meeting That Are Being Delivered To Your Family Member In The Community

- Yes: KRC (N = 22) - 91%, CA Average (N = 779) - 89%
- No: KRC (N = 22) - 9%, CA Average (N = 779) - 11%